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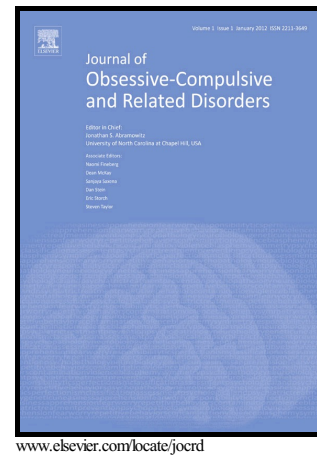
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# Author's Accepted Manuscript

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**Development of a brief psychoeducational group intervention for carers of people with  
Hoarding Disorder: A proof-of-concept study**

Claire Thompson<sup>a\*</sup>, Lorena Fernández de la Cruz<sup>b</sup>, David Mataix-Cols<sup>b</sup>, and Juliana

Onwumere<sup>a</sup>

<sup>a</sup>Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, England.

<sup>b</sup>Centre for Psychiatric Research and Education, Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden.

\*Corresponding author: Claire Thompson, Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's College London, 16 De Crespigny Park, London, SE5 8AF. Email: Claire.c.thompson@kcl.ac.uk

**ABSTRACT**

**Background**

Hoarding Disorder (HD) is a burdensome and disabling mental health condition, which is associated with substantial functional disability and represents a major public health issue. Hoarding problems can also have a major adverse impact on the relatives/carers of people who hoard. The current study evaluated the impact and acceptability of a brief psychoeducational group intervention for carers of people with HD.

**Methods**

Twelve family carers of people with HD took part in a six-week manualised psychoeducational group. Measures of knowledge about HD, caregiving experiences,

expressed emotion, wellbeing, distress, and coping styles were taken at pre-, post-intervention, and 1-month follow-up.

## Results

The results indicated significant improvements post-intervention in carer reported wellbeing, positive experiences of caregiving, and understanding of HD. No changes were observed in carer reports of caregiver burden, distress, expressed emotion, and coping styles. Satisfaction and perceived helpfulness were high.

## Conclusion

A relatively brief, group-based intervention can support carers in their understanding of HD and positively impact on their own wellbeing and relationship with their relative with HD. Replication with a larger sample and controlled design is required.

**Keywords:** hoarding disorder, group interventions, caregivers, carers.

## 1. INTRODUCTION

Hoarding disorder (HD) is a disabling mental health condition with a prevalence of at least 1.5% in the general population (Nordsletten, Reichenberg, et al., 2013). It is mainly characterised by persistent difficulties discarding possessions. The resulting build-up of clutter is associated with substantial disability and impairment in various areas of functioning, including poorer physical health and social and work-related difficulties (Ong, Pang, Sagayadevan, & Chong, 2015; Saxena et al., 2011).

It is increasingly recognised that, as well as the adverse impact on the individual, HD can have a substantial negative impact on family members. Almost two thirds of people with hoarding difficulties are able to identify relationship problems with family members due to their hoarding (Frost & Gross, 1993), and living with a hoarding family member in

childhood has been associated with greater childhood distress and family strain (Tolin, Frost, Steketee, & Fitch, 2008). Relatives of people with HD report equivalent levels of functional impairment in some areas of functioning, including emotional distress, to those of the person with HD themselves (Drury, Ajmi, Fernández de la Cruz, Nordsletten, & Mataix-Cols, 2014). Moreover, the experience of carer burden is not dissimilar to levels reported by carers in other well-studied health conditions including dementia (Drury et al., 2014). Park and colleagues (Park, Lewin, & Storch, 2014) looked at influences on parent-offspring relationships in HD and found that as hoarding severity increased, family relationships became less functional and this in turn negatively impacted the quality of parent-offspring relationships. Expressed emotion (EE), a measure of the quality of the caregiving relationship, is a widely studied concept within the caregiving literature yet to be studied in HD. High EE, defined in terms of elevated levels of criticism and/or emotional over-involvement, has been linked to poorer patient outcomes and higher levels of caregiver burden in severe mental illness including schizophrenia spectrum and affective disorders (Bebbington & Kuipers, 1994; Raune, Kuipers, & Bebbington, 2004).

In the aforementioned study comparing relatives to sufferers of HD (Drury et al., 2014), factors such as cohabitation with the relative and the level of squalor (e.g., unhygienic conditions) appeared particularly predictive of the burden and impairment experienced. Individuals with HD characteristically fail to recognise their symptoms and the impact these have on others as problematic, which can also serve as a source of family conflict and distress (Drury et al., 2014; Frost, Steketee, Youngren, & Mallya, 1999; Tolin, Fitch, Frost, & Steketee, 2010). As well as poor insight, sources of family distress include perceived stigma and a lack of available information about HD (Sampson, 2013; Wilbram, Kellett, & Beail, 2008). Several studies have indicated that families may get caught in a cycle

of accommodation to HD (for example, avoiding talking about the hoarding, providing extra storage space in their own home for items, or discarding items in secret) (Drury et al., 2014; Nordsletten et al., 2014; Vorstenbosch, Antony, Monson, & Rowa, 2015; Wilbram et al., 2008). Such behaviours are often associated with increased carer distress and rejecting attitudes toward the person with HD (Vorstenbosch et al., 2015).

To date the main treatment efforts in HD have focused almost exclusively on the person who hoards (Muroff, Bratnott, & Steketee, 2011). However, improvement in HD symptoms has proved to be limited thus far. Data from a recent meta-analysis of cognitive-behavioural therapy for HD (Tolin, Frost, Steketee, & Muroff, 2015) showed that, on average, only 35% of patients demonstrated clinically significant change, despite lengthy and intensive treatment. In recent years, however, there has been greater attention on carers, with preliminary research findings suggesting they could benefit from educational and support interventions to facilitate their understanding of and adaptive coping with the condition (Büscher, Dyson, & Cowdell, 2014; Chasson, Carpenter, Ewing, Gibby, & Lee, 2014; Sampson, Yeats, & Harris, 2012; Tompkins, 2011; Wilbram et al., 2008). One case report (Tompkins, 2011) described a 'harm reduction' approach for families of people with HD and low motivation to seek help, with improvement in clutter and the motivation of the person with HD to seek help post-intervention, although no outcome measures were reported. Another case report (Ale, Arnold, Whiteside, & Storch, 2013) tested family-based cognitive-behaviour therapy (CBT) for a child with hoarding behaviour, with reductions in scores on the Children's Saving Inventory – a parent-reported measure of hoarding symptoms in children (Storch et al., 2011). Two small-scale studies in the United States have evaluated carer-only interventions in HD. Sampson and colleagues (2012) piloted a six week psychoeducational-style support group for eight carers of people with clinically significant

hoarding. No quantitative outcomes were reported, but six participants completed qualitative interviews post-intervention. The results highlighted subjective improvements to participants' knowledge and understanding of hoarding, levels of distress, and positive interactions with their relative. Chasson and colleagues (2014) reported the results of a 14-week 'family-as-motivators' intervention package for nine carers. The package included modules on psychoeducation, harm reduction, motivational interviewing training, and family accommodation prevention. The key findings suggested improvements in the use of helpful coping strategies, hopefulness, use of motivational interviewing strategies, and understanding of hoarding. There were some notable improvements in the impact of HD on the family from pre-to-mid training, but no significant change on actual HD symptoms as reported by carers. It was important to note that four of the nine carers (44%) dropped out before the end of treatment, which limited the interpretation of the results. Further, aside from the small sample size, hoarding in the relative was assessed only via a brief screening measure (the Hoarding Rating Scale Interview [HRS-I]; Tolin, Frost, et al., 2010), and thus it was unclear to what extent relatives met full HD criteria.

Family focused interventions have the potential to be beneficial for several reasons. It is known that many people with HD do not seek treatment (Tolin, Frost, Steketee, Gray, & Fitch, 2008), under-report their symptoms (Dimauro, Tolin, Frost, & Steketee, 2013), and often drop out of treatment (Gilliam et al., 2011; Tolin, Frost, & Steketee, 2007; Turner, Steketee, & Nauth, 2010). Informal carers (families) can be instrumental in encouraging their relative with hoarding difficulties to seek help and/or enlist the support of external agencies and professionals. Further, family-based interventions are a well-established therapeutic approach employed successfully in a range of severe mental health conditions (e.g., obsessive-compulsive disorder, schizophrenia spectrum disorders, bipolar disorder)

(Miklowitz, 2006; Pharoah, Mari, Rathbone, & Wong, 2010; Renshaw, Steketee, & Chambless, 2005). In psychosis, brief carer-based psychoeducation groups have yielded positive outcomes in terms of increased knowledge about the condition, improved coping and quality of life, and reductions in distress (Sin & Norman, 2013; Yesufu-Udechuku et al., 2015).

The current paper presents findings from a proof-of-concept study investigating the impact of a brief psychoeducational group intervention for carers of people with HD. It will examine the feasibility and acceptability of the intervention, and review the effects of the group on carer understanding of HD and levels of wellbeing, burden, and coping efforts. Given the literature reviewed here regarding the negative impact of HD on carers, the focus will be on carer outcomes rather than training the carer in specific methods to reduce the hoarding itself, in contrast to several of the previous studies in this area (Ale et al., 2013; Chasson et al., 2014; Tompkins, 2011). It was hypothesised that, post intervention, carer knowledge about hoarding, levels of wellbeing, positive experiences of caregiving and adaptive coping would improve. It was also hypothesised that carers' levels of distress, burden, and EE would show significant reductions after the intervention.

## **2. METHODS**

### **2.1 Participants**

Twelve carers participated in two separate groups, with six participants in each group. The sample consisted of carers of people who met DSM-5 criteria for HD (according to the Structured Interview for Hoarding Disorder (SIHD) (Nordsletten, Fernández de la Cruz, et al., 2013), administered with the carer. A 'carer' was defined as a parent, relative, spouse, or



partner of an individual with likely HD, who was in regular weekly contact with the hoarding individual, including telephone contact. Similar definitions of carers have been employed in previous research with carers from other mental health conditions (e.g., Kuipers et al., 2006). The inclusion criteria were: a) age 18 or over and b) able to travel to group sessions. Exclusion criteria were: a) insufficient command of English language to complete measures and engage in group intervention and b) meeting criteria for HD themselves (screened using the clinical cut-off of the HRS-I (Tolin, Frost, et al., 2010)). Participants were recruited through advertisements placed on self-help online forums for hoarding in the UK (e.g., helpforhoarders.co.uk; childrenofhoarders.com). The study was approved by King's College London's Research Ethics Committee (reference PNM/13/14-28).

## 2.2 Measures

Social demographic information was collected from all participants including gender, age, ethnicity, amount of contact with the person who hoards, and their relationship to the person.

The SIHD (Nordsletten, Fernández de la Cruz, et al., 2013), a semi-structured clinical interview for diagnosing HD, was conducted over the phone with the carer to establish whether the hoarding relative would meet likely criteria for HD. The first author (CT) conducted the interviews and, in cases of diagnostic uncertainty, consulted LFC, who is experienced in assessing HD. To estimate the severity of the relative's HD, the HRS-I (Tolin, Frost, et al., 2010), a brief measure assessing the key diagnostic features of HD (e.g. difficulty discarding), was rated by the carer. A score of 14 or more indicates clinically significant hoarding symptomatology. The HRS-I has good reliability and validity (Tolin et al., 2010). Additionally, carers rated the level of clutter at their relative's home using the Clutter

Image Rating scale (CIR; Frost, Steketee, Tolin, & Renaud, 2008), on which a score of 4 or above in any room is usually taken as clinically significant levels of clutter. The CIR has good reliability and internal consistency (Frost et al., 2008). Relative ratings of HD have been shown to correlate highly with self-report (Drury, Nordsletten, Ajmi, Fernández de la Cruz, & Mataix-Cols, 2015).

To assess carers' understanding of HD, the authors developed a seven-item multiple choice 'Knowledge about hoarding' questionnaire which included questions about common symptoms, causes, and treatments for HD. Four response options were provided for each question and participants were asked to select one of them. The maximum possible score on this measure was seven, (range 0-7). The measure is available on request from the first author.

The Experiences of Caregiving Inventory (ECI; Szmukler et al., 1996) is a self-report measure used widely in the mental health caregiving literature to measure negative experiences of caregiving (burden) and positive caregiving experiences (e.g. Addington, Coldham, Jones, Ko, & Addington, 2003). The ECI consists of 10 subscales: two positive (rewarding personal experiences and good aspects of the relationship) and eight negative (e.g., stigma, effects on the family, problems with services, difficult behaviours) which are scored separately. The negative scale is 52 items (maximum score=208) and the positive scale 14 items (maximum score=56), with higher scores denoting greater positive and negative caregiving experiences. The ECI has good construct validity and reliability (Joyce, Leese, & Szmukler, 2000; Szmukler et al., 1996). In the current sample the internal consistency of the positive ECI was  $\alpha=.872$  and the negative ECI  $\alpha=.943$ .

The Five Minute Speech Sample (FMSS; Magaña et al., 1986; Malla, Kazarian, Barnes, & Cole, 1991) was conducted over the telephone and coded for a measure of EE. The FMSS is the best known and most widely used alternative to the 'gold standard' measure of EE, the Camberwell Family Interview (Vaughn & Leff, 1976). In the FMSS, carers are asked to speak for five minutes about their thoughts and feelings about the person they care for. The interview is recorded, transcribed, and then coded for overall level of EE (high or low), criticism and emotional over involvement (EOI). In this study, an interrater reliability analysis was performed to determine consistency among raters, which was found to be good (Kappa=0.75).

The Brief COPE was used to assess coping strategies (Carver, 1997). In line with similar carer intervention studies (Kuipers et al., 2006; Onwumere et al., 2011; Raune et al., 2004), the composite avoidant subscale was employed, which sums the individual subscales of behavioural disengagement, self-distraction, substance use, and denial (maximum possible score=32). All other subscales had a maximum possible score of 16. The Brief COPE has good internal reliability according to the original validation of the scale (Carver, 1997).

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to assess psychological distress in the carers. A score of  $\geq 11$  on either the anxiety or the depression subscale is indicative of probable clinical levels of distress. The HADS has well-established psychometric properties (Bjelland, Dahl, Haug, & Neckelmann, 2002). In the current sample the internal consistency was high for the anxiety and depression subscales ( $\alpha=.740$  and  $\alpha=.847$  respectively).

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007) was used to assess the wellbeing of the carers. Statements related to various aspects of

wellbeing are rated from 1-5 (maximum possible score=70). The WEMWBS has good validity and reliability and has been demonstrated to have good responsivity to health interventions (Maheswaran, Weich, Powell, & Stewart-Brown, 2012). The internal consistency was high in the current sample ( $\alpha=.872$ ).

After each group session, participants rated how satisfied they were with the session and how helpful they had found it on a scale ranging from 0 to 10. Brief qualitative feedback was elicited from group participants at the end of the intervention on their experience of the group.

The SIHD was completed only at baseline and the FMSS and knowledge about hoarding questionnaire were completed only at baseline and at post-treatment. All other measures were completed at baseline, post-intervention, and 1-month follow-up.

### 2.3 Group intervention

The groups consisted of weekly two-hour sessions for six weeks, followed by a one month follow-up session. The groups were held in a university building and were each facilitated by three clinicians; a doctoral training level clinical psychologist (CT), a research clinical psychologist with specialism in HD (LFC), and a clinical psychologist with specialism in carer interventions (JO). The facilitators met weekly (between sessions) for supervision.

The intervention protocol was manualised (Thompson, Fernández de la Cruz, Mataix-Cols and Onwumere, unpublished). An outline of the session content is presented in **Table 1**.

**Table 1. Content of the psychoeducational intervention.**

<b>Session 1</b>	<p><b>Emotional processing:</b> Understanding the family experience of hoarding and impact on relationships. Addressing common emotional issues faced by relatives of people who hoard such as loss, guilt, and frustration. <u>Goal:</u> Normalisation and cognitive reappraisal in the context of severe problems.</p>
<b>Session 2</b>	<p><b>Understanding Hoarding Disorder:</b> Psychoeducation regarding definition, symptoms, and proposed causes of HD. <u>Goal:</u> Improve carer attributions about relative and relationship quality; improve style of interaction with relative; reduce pressure on carer to clear house or make relative clear house; address concerns about carer developing the condition.</p>
<b>Session 3</b>	<p><b>Treatment options, tips for helping:</b> Available treatments, difficulties and challenges in treatment, things to do to support the relative. <u>Goal:</u> Provide carer with useful resources to deal with their relative's hoarding.</p>
<b>Sessions 4-5</b>	<p><b>Problem-solving:</b> Common difficulties faced by caregivers of hoarders, for example worries about the relative's safety. <u>Goal:</u> Optimise adaptive coping with specific problems; maintaining a relationship in the context of emotional reactions towards relative, cognitive reappraisal of problems, and helpful reactions.</p>
<b>Session 6</b>	<p><b>Promoting carer well-being:</b> Addressing carer specific health and well-being needs. <u>Goal:</u> Improve carer strategies to look after themselves in terms of physical and mental well-being (e.g., sleep, relaxation, support networks); distancing from immediate problems, encouragement to pursue own interests.</p>
<b>Follow-up</b>	<p><b>Monitoring progress and troubleshooting:</b> Semi-structured session, flexible to the needs of the group.</p>

## 2.4 Statistical Analyses

Statistical analyses were conducted in SPSS v22 for Windows. Paired t-tests for quantitative variables were used to compare participant's pre-, post-treatment, and 1-month follow-up

outcomes. To correct for multiple testing, the significance value was set to .02 (.05 divided by 3; pre, post and follow-up). An exact McNemar test was used to compare EE before and after the intervention. All tests were two-tailed.

### **3. RESULTS**

#### **3.1 Participant Characteristics**

The mean age of participants was 40.17 years (SD=16.13, range: 21-73) and nine were female (75%). Eight carers (66.7%) were classified as White British or Other White, and four (33.3%) were from Black and Minority ethnic groups. Half of the group was married or cohabiting (n=6) and the remainder were split evenly between those who were single (n=3) and separated or divorced (n=3). Half of the sample were working full-time or part time (n=6) and the rest were either students (n=2), unemployed (n=2), volunteering (n=1), or retired (n=1).

Regarding the familial relationship with the person with HD, nine participants were the children of a parent with HD, one participant was a step-daughter, one was a parent of a son with HD, and one was a nephew of an uncle with HD. None of the carers were related to each other. Two members of the group were currently living with their hoarding relative (16.7%). The median number of hours of contact with the relative was 11.5 per week (range=1-50).

#### **3.2 Group attendance**

The mean number of group sessions attended by participants was 4.92 (SD=0.99; range=3-6) out of a total 6. All participants completed the baseline measures, eleven completed the post-intervention measures, and eight completed the 1-month follow-up. The four

participants who did not attend follow-up cited other commitments on the evening of the scheduled follow-up session.

Demographics and HRS-I total scores of participants who provided full data sets versus those who missed 1 or more data points were compared. Mann-Whitney U and chi-square goodness of fit comparisons between the groups revealed that people who did not complete the follow-up measures were more likely to be White British and not living with their hoarding relative. However, given the small sample sizes of the compared groups, these differences in demographics are likely to be negligible. Importantly, there were no differences in the severity of the hoarding symptoms of their index relative as measured by the HRS-I ( $p=0.72$ ), nor on any of the main outcome measures (all  $p$ 's  $\geq .05$ )."

### **3.3 Understanding Hoarding and caregiving experiences**

There was a significant increase in the scores on the knowledge about hoarding questionnaire from pre to post-intervention (**Table 2**). Carer wellbeing improved significantly from pre to post-intervention, and again from post to follow-up, as measured by the WEMWBS (Tennant et al., 2007). There was no significant change in carer distress levels over the three time points, indicating the intervention had no effect on levels of distress (either anxiety or depression) on the HADS. Similarly, there was no significant change in caregiver burden following the intervention or at 1-month follow up, as assessed by the negative scale of the ECI.

Positive experiences of caregiving (ECI positive) improved significantly from pre- to post-intervention, and from pre to follow-up, but not between post-intervention and follow-up. There were no significant differences in the use of the less adaptive (i.e. avoidant) or

other coping strategies after the intervention as measured by the Brief-COPE ( $p's > .05$ ).

Levels of emotional support coping showed a significant increase from post to follow-up.

No changes were observed to carer appraisals about the quality of the relationship (EE) after the intervention ( $p = .625$ ).

**Table 2. Results of the group intervention.**

Variable	Means (SD)			Pre-post (n=11)		Pre-FU (n=8)		Post-FU (n=8)	
	Pre- intervention (N=11)	Post- intervention (N=11)	1-month follow- up (N=8)	T	P	t	p	t	p
<b>Knowledge about hoarding</b>	4.81 (.98)	5.81 (.60)		-2.08	.019*				
<b>ECI (Caregiving)</b>									
ECI negative	87.91 (30.64)	87.27 (36.92)	89.00 (8.45)	.12	.906	-.95	.373	-.63	.546
ECI positive	24.91 (10.41)	28.91 (10.00)	25.63 (9.27)	-2.97	.014*	-3.94	.006*	.31	.769
<b>Brief COPE (Coping)</b>									
Avoidant coping	12.36 (2.73)	12.45 (3.05)	12.50 (2.27)	-.08	.938	.26	.802	.11	.913
Active coping	5.45 (2.02)	6 (1.41)	5.25 (1.67)	-1.20	.258	-.15	.882	1.26	.250
Emotional support	4.45 (1.75)	4.45 (1.57)	5.25 (1.49)	.00	1	-1.39	.217	-3.00	.020*
Instrumental coping	5.09 (1.81)	5.27 (2.10)	5.12 (1.96)	-.36	.724	-1.00	.351	-.16	.879
Reframing	3.91 (1.51)	4.36 (1.86)	3.37 (1.51)	-1.84	.096	-.23	.826	.31	.763
Planning	5.82 (1.25)	6.37 (1.27)	5.37 (1.30)	-1.34	.211	.00	1	1.36	.217
Humour	4.18 (1.47)	3.73 (1.42)	3.5 (1.31)	1.05	.320	.51	.626	-.68	.516
Acceptance	5.09 (1.58)	5.27 (1.68)	5.13 (1.36)	-.61	.553	-.63	.549	-.61	.563
Religion	3.10 (1.38)	3.36 (1.36)	3.50	-1.94	.082	-1.53	.170	-.61	.563



			(1.60)						
<b>HADS (anxiety)</b>	8.45 (3.39)	9.45 (4.16)	8.75 (2.71)	-1.01	.337	-1.16	.285	-.21	.844
<b>HADS (depression)</b>	5.18 (4.42)	4.45 (4.20)	4.50 (3.93)	1.39	.195	.00	1	-4.44	.677
<b>WEMWBS (Wellbeing)</b>	29.18 (7.07)	33.55 (10.28)	45.25 (8.92)	-2.81	.018*	-5.05	.001*	-3.61	.009*

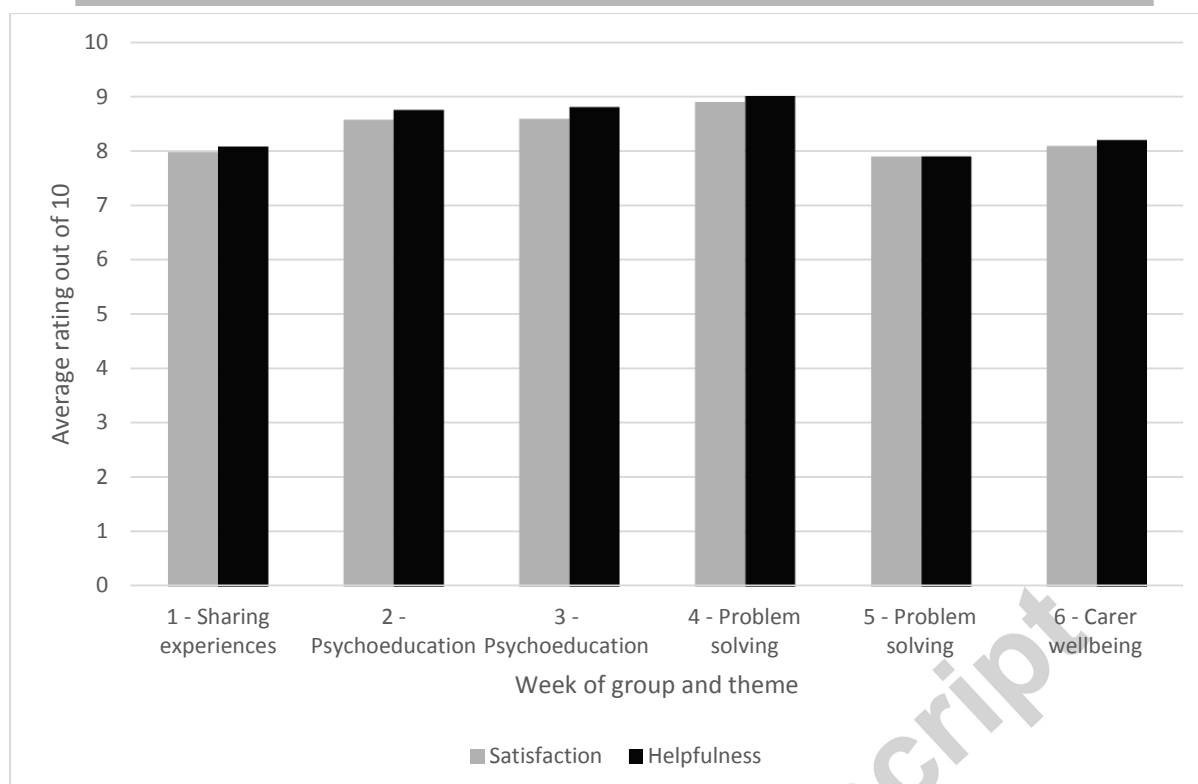
Abbreviations: *ECl*=Experiences of Caregiving Inventory; *HADS*=Hospital Anxiety and Depression Scale;

*WEMWBS*=Warwick-Edinburgh Mental Wellbeing Scale. \*=significant at  $p \leq .02$ .

### 3.4 Intervention acceptability

Overall satisfaction (mean of 6 sessions=8.35; SD=0.40) and helpfulness (mean of 6 sessions=8.46; SD=0.45) ratings were high over the duration of the group (**Figure 1**). Qualitatively, participants reported a range of gains, including the benefit of meeting others in a similar position and the usefulness of the psychoeducational material and practical problem solving sessions.

**Figure 1: Acceptability ratings by week of the group.**



#### 4. DISCUSSION

This study aimed to examine the feasibility, acceptability, and effectiveness of a brief psychoeducational group intervention. In line with predictions, following group attendance there were notable improvements in carers' understanding of hoarding disorder, reports of positive caregiving experiences, and wellbeing. However, there were no significant changes in carer reports of distress, caregiving burden, avoidant coping, and appraisals about the quality of their caregiving relationship. Quantitative and qualitative feedback suggested that the group was well-received by participants.

The results support the feasibility of offering group-based support to HD carers. HD is associated with stigma and relatives often report secrecy around the hoarding (e.g., Wilbram et al., 2008). The relatives in the current study reported feeling isolated and thus welcomed the opportunity to share experiences, reflect on difficulties, and learn from peers

in a similar situation. Participants rated sessions as helpful and gave positive feedback about the content and length of the group. The take up of the intervention and attendance was good, although there was some dropout at follow-up. Participants indicated that the inclusion of psychoeducation, a supportive group setting, and 'practical' problem solving tips were important components of the group. Some participants indicated a wish for an increased emphasis on practical strategies to help their hoarding relative (e.g., how to support them to declutter) and more role-plays for practising problem solving. As was suggested by Sampson et al. (2012), carers in the current group confirmed that a group size of around 6 was preferable.

In terms of effectiveness, improvements in wellbeing were particularly encouraging, given that baseline levels fell well below the general population average (Stewart-Brown & Janmohamed, 2008). Wellbeing may have improved through a variety of mechanisms, including the group format. The group was designed to be a safe and supportive environment where participants were able to obtain mutual support from others with similar experiences, with whom they could share ideas for coping and managing the problem, and recognise that they were not alone in their concerns and frustrations, which may have helped to enhance wellbeing (Chien & Norman, 2009; Citron, Solomon, & Draine, 1999; Cuijpers, Hosman, & Munnichs, 1996). Participants in Sampson et al.'s (2012) group for HD carers also identified the social support element as particularly helpful.

Peer-based social support may also have plausibly contributed to the observed increases in positive experiences of caregiving. Similar findings have been reported in a study of psychosis carers; for example, Chen and Greenberg (2004) found that support received from support groups and professionals was positively associated with carer reports

of positive caregiving experiences. Given that relatives of people with HD are less likely to have received professional support, due to the current dearth of services for people with HD and their families, the peer support is likely to have been particularly important. It is of note that it has been a fairly recent move in the caregiving literature to acknowledge the importance of positive caregiving experiences as well as burden, and to focus on building strengths as well as reducing problematic aspects in interventions (Bauer, Sterzinger, Koepke, & Spiessl, 2013; Veltman, Cameron, & Stewart, 2002).

Group members reported finding the psychoeducation sessions invaluable, especially given that there was little information available elsewhere on the disorder. Learning more about the symptoms of HD and the proposed causes and treatments may have contributed to improved appraisals of their relative's behaviour, potentially also impacting on positive appraisals of caregiving and positive wellbeing. This finding, along with evidence from the previous carer intervention studies in HD (Chasson et al., 2014; Sampson et al., 2012), underscores the need and importance of supporting carers to better understand the condition.

Contrary to predictions, no improvements to carer distress, burden, or EE levels were observed following the intervention. Several studies have noted that psychoeducational carer interventions can struggle to reduce burden and distress levels (Sin & Norman, 2013), and have found little change in overall EE status after brief psychoeducational intervention (e.g., Eisner & Johnson, 2008). It could be argued that positive changes to burden and psychological distress will only follow once the relatives' symptoms reduce (Szmukler et al., 2003), or following family-based interventions where the hoarding relative participates (Lobban et al., 2013) or individual carer intervention (Roddy,

Onwumere, & Kuipers, 2015). The observation of increases in wellbeing and positive aspects of caregiving scores but lack of significant change in carer reports of burden offers further support for the independence of positive wellbeing from negative emotional states and appraisals and their underlying processes and functions. We know that individuals can report positive improvement and emotional states even while stressors continue to be present (Folkman & Moskowitz, 2000; Fredrickson, 1998, 2001). It is also interesting to observe the particularly high scores on the burden scale of the ECI in this population, which were higher than those found in caregiving populations of other mental disorders (e.g., Martens & Addington, 2001; Treasure et al., 2001). Thus, another potential explanation for the lack of change observed may be that this is a particularly burdened group of carers who may require further intervention.

We also did not observe changes to coping styles, including avoidant coping, after the intervention. However, mean baseline levels of avoidant coping were slightly lower than has been previously reported in psychosis carer groups (e.g. Onwumere et al., 2011; Raune et al., 2004), and thus it is possible that this coping style is less common in HD carers. Ways of coping and improving coping styles in HD carers also merit further study.

Though preliminary, the results of the group intervention can offer implications for clinical practice. A brief structured intervention for carers may help to support important developments in how they understand and make sense of the illness, and improve their own wellbeing and caregiving experience. Carer interventions should be tailored to support carers with the specific challenges posed by having a relative with HD and include a psychoeducation component. Participants in the current group and in previous studies (e.g.,

Sampson et al., 2012) indicated that ongoing support for family members may be desired in addition to brief focussed interventions.

The study had some notable strengths. In contrast to previous carer intervention studies (Chasson et al., 2014; Sampson et al., 2012), carers were recruited via publicly accessible forums rather than through professional services, meaning that our sample was likely to be less biased toward those whose relatives with HD had better insight. In addition, the group intervention used a theoretically informed protocol which targeted several of the components identified in a recent systematic review of carer interventions to be most helpful for carers of individuals with severe mental health conditions (Lobban et al., 2013), including stress management, psychoeducation, problem solving and social support. This was also the first carer study to thoroughly assess HD in the relative with a structured interview (the SIHD; Nordsletten, Fernández de la Cruz, et al., 2013), increasing the likelihood that the hoarding relatives would have met DSM-5 criteria for HD.

The study has some limitations. First, though novel, the sample size and the uncontrolled design mean the results require replication in a larger scale study. Second, there was some attrition in completing measures at post and follow-up, although there was less dropout than in previous intervention studies (e.g., Chasson et al., 2014; Sampson et al., 2012). Third, the 'Knowledge about hoarding' questionnaire and the session satisfaction measures were not validated and, thus, results based on these measures should be interpreted with caution. Fourth, the SIHD and FMSS were conducted via telephone, which potentially posed an issue for the FMSS which is usually conducted face-to-face, although previous studies have found good correspondence between telephone and face-to-face administration of the FMSS (Beck, Daley, Hastings, & Stevenson, 2004). Though previous

studies have shown good reliability between carer reports and direct reports on the SIHD (Drury et al., 2015), it is possible that some participant's relatives may not have met full HD criteria. Fifth, no direct assessments of patient symptomatology or accommodating behaviours in the family were undertaken after the group, and thus it remains to be studied whether carer interventions may exert any direct or indirect effects on HD symptoms in the relative or family accommodation to symptoms, as was recently investigated in relatives of people with OCD (VanDyke, Pollard, Harper, & Conlon, 2015). Finally, the participants in the current study were predominantly adult children who did not live with their hoarding relative, and thus, results cannot be reliably generalised to other groups of carers (e.g., co-resident spouses). Further exploration of any particular additional needs of carers living with, or having high rates of contact with, the person who hoards is warranted. It is possible that co-resident carers may have differential rates of reported distress and social network difficulties, as has been found in other caregiving populations. For example, Smith et al., (2014) found increased psychiatric symptomatology among carers who provided more than 10 hours a week of care to their relatives with psychosis.

#### **4.1 Conclusions**

Carer-only interventions have the potential to alleviate some of the negative effects of HD on the family and relationships. The results of the proof of concept study indicate that a brief psychoeducational group may improve the knowledge, experiences of caregiving, and wellbeing of HD carers, which can be maintained at 1-month after the group. The study requires replication in a larger controlled trial.

Accepted manuscript



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#### Highlights

- We piloted a six-week group intervention for carers of people with Hoarding Disorder.
- Carers reported improvements in wellbeing and positive experiences of caregiving.
- Carer knowledge about Hoarding Disorder also improved after the intervention.
- Carers distress levels, burden, expressed emotion, and coping styles did not change.
- The intervention was well received with high reported satisfaction and helpfulness.